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ABSTRACT

The two documents describe California's efforts to collect information on the needs of Spanish speaking parents of developmentally disabled children. Fiesta Educativa was the name of a conference offering workshops and exhibits to more than 1,000 parents and professionals. During the Third Annual Fiesta, information was collected via questionnaires, small group discussions, and discussion booths. A final report focuses on the information gathering approach, with separate sections on methodology, results, and discussion. The development of instruments, training of interviewers, and analysis of data from the Fiesta Educativa are summarized. Results are presented according to parent information, vocational education and services, and professional information. Parent information focuses on child's age, sex, and disability; parent's perception of disability; services provided; family factors; parent training and involvement in child's special education; and parental needs, problems, and suggestions. Cross tabulation of the data reveals that parents' concerns were affected by child's age. Results on the topic of vocational education identify parents' concerns (such as lack of information about services and cultural considerations in vocational programs). Professional information deals with work settings, client age, and views of parent needs (such as more bilingual foster and respite care). Both parents and professionals pinpoint language barriers and inadequate information as central problems. A discussion section considers advantages and disadvantages of the data collection approaches. Among four appendixes are guidelines for discussion group leaders and recorders and sample parent and professional questionnaires. (CL)

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INFORMATION GATHERING AT THE FIESTA EDUCATIVA '80

Final Report
Executive Summary

October, 1980

Fiesta Educativa Sponsored by
El Comité Estatal Pro-Fiesta Educativa para
Personas con Incapacidades del Desarrollo

Information Gathering Conducted by
SWRL Educational Research and Development
4665 Lampson Avenue
Los Alamitos, California

With Funds Provided by
California Department of Developmental Services
California Department of Rehabilitation

EC 151612

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ACKNOWLEDGMENTS

This information-gathering effort required the involvement and support of many people. Funding was provided by the California Departments of Developmental Services and Rehabilitation. We gratefully acknowledge the efforts of the Los Angeles County Inter-Regional Center Committee for the Spanish-Speaking, and the Eastern Los Angeles Regional Center for the Developmentally Disabled. The help of Irene Martinez, our primary IRC liaison, was invaluable to us. Many thanks also go to others whose interest and assistance forwarded this work: SWRL staff, Fiesta information collection staff from several Regional Centers and local service agencies, and the many parents and professionals who contributed so much to the information collection.

In addition to its potential value for program planning and development, this study, and the Fiesta of which it was a part, represent a model for us. They are the best examples we know of real collaboration among many caring and skilled people, parent and professional alike. We are grateful for the privilege of participating.

Barbara Lasser, Project Director
William Brock, Senior Project Staff

INTRODUCTION

Currently, there is little information available regarding the specific service needs of Spanish-speaking parents of developmentally disabled children. Available data do indicate, however, that many existing services for the developmentally disabled are underutilized by the Spanish-speaking population (Chan, 1980; Birman, 1979; Delgado, 1980). Although a combination of factors probably contribute to this pattern of underuse, many social service professionals believe that language barriers are a major factor. To some, agencies that serve the Spanish-speaking population appear inadequately staffed to respond to the communication needs of their clients. Lack of sensitivity to cultural and linguistic characteristics that affect client needs may be a concomitant of this problem (Marion, 1980). Such examples suggest the complex interactions that language differences may represent in practice.

The Spanish-speaking population in California is growing at a rapid rate (U.S. Bureau of the Census, 1980). As the population increases, so does the need to provide adequate services for developmentally disabled Spanish-speaking clients. Individuals who are both developmentally disabled and non-English-speaking may require special services, particularly when they are also members of low income families (Chan, 1980). A first step toward achieving a more responsive service system is to obtain accurate information about this population, their perceived needs, and major problems. Fiesta Educativa '80 provided a rare opportunity to collect such information from parents, and from the professionals who work with them.

THE FIESTA EDUCATIVA

Fiesta Educativa was the third annual educational conference designed specifically for Spanish-speaking parents of developmentally disabled individuals. The conference was sponsored by the Comité Estatal Pro Fiesta Educativa para Personas con Incapacidades del Desarrollo and planned in cooperation with the Los Angeles County Inter-Regional Center Committee for the Spanish-Speaking. A full day of workshops, seminars, and exhibits was offered to more than 1,000 parents and professionals from California and nearby states.

Each year the Fiesta focuses on several major goals. The Fiesta provides Spanish-speaking parents of the developmentally disabled with information, in Spanish, about available services and programs. The Fiesta is designed to provide information and training related to specific areas of developmental disability. The conference also promotes interaction and cooperation among Spanish-speaking parents and professionals who serve the Hispanic community.

INFORMATION GATHERING AT THE FIESTA

Fiesta Educativa '80 provided an occasion to collect information about the specific needs of the Spanish-speaking community in the area of services for the developmentally disabled. This needs-sensing activity was conducted at the Fiesta by SWRL Educational Research and Development. The information obtained through the needs-sensing can be used by agencies and organizations attempting to improve and modify services to better meet the needs of the Spanish-speaking community.

During the Fiesta, information was collected through three mechanisms:

1. **Questionnaires.** Two questionnaires were used for data collection: one for parents and one for professionals. Questionnaires were included in each participant's registration packet, and were available in both Spanish and English.

2. **Small Group Discussions**. Small group discussions on service needs were conducted in Spanish by trained group leaders. The group leaders maintained focus on five central discussion questions, but also provided for the open communication needed by participants to express more fully their needs and experiences. Each group discussion was also attended by a trained recorder who documented the comments made and needs identified by parents during the sessions. They included questions about the characteristics of the developmentally disabled client, parent knowledge and attitudes, and major service needs and problems as perceived by parents and professionals.

3. **Discussion Booths.** Two to four discussion booths operated during the entire day, staffed by trained personnel representing the Regional Centers and other social service agencies. These booths were designed to provide conference participants an opportunity to discuss their needs in a private, individual setting. Discussion booth staff also assisted parents who had questions or difficulty in completing their questionnaires.

Final Reports of this study were prepared for the California Departments of Developmental Services and Rehabilitation. This report summarizes those documents.

PARENT INFORMATION

Three-hundred seventeen parents completed questionnaires at the Fiesta. The average age of the developmentally disabled children represented was eight years. The most commonly reported disabilities were mental retardation (46%) and cerebral palsy (11%). Fifty percent of the parents rated their child's disability as moderate, 23% as mild, and 27% severe. Seventy-four percent of the children were registered with one of the six Regional Centers in Los Angeles county.

Over half (55%) of the parents with school-aged children have attended an Individualized Education Plan (IEP) meeting; however, another third of the parents responding to the questionnaire were not familiar with an IEP and did not recognize the term.

A small proportion of the respondents described themselves as actively involved in parent training or other parent groups. Seventy percent stated they had attended either the Fiesta only, or the Fiesta and one other parent training program in the past two years. Two-thirds of the parents did not belong to a parent or advocacy group.

On the questionnaire, parents rated lack of information about existing services as their greatest problem in obtaining services for their children. This problem was noted by 29% of the respondents. Five other problems received approximately equal ratings (15% to 17%): agency staff couldn't speak Spanish, lack of transportation, agency too slow, lack of cooperation from professionals, and too much paper work.

During the discussion groups, parents described problems related to communication barriers with service agencies—barriers that they feel extend far beyond language differences. Such barriers were frequently described in terms of lack of understanding and sensitivity to Hispanic culture.

Some of the information collected related to how independent parents feel their children could or should be. A large percentage of parents (62%) said they would like to have respite care services from time to time. They were largely unsure (61%) about whether sex education in school would be appropriate for their children. Most parents (65%) said their children would probably live at home as adults. Less than one-third (29%) thought their children would have jobs as adults; 50% were not sure.

On the whole, these parents are skeptical of their children's ability to live independently as adults. They seem receptive to the concept of respite care and other family support services such as those offered at the Regional Centers. At the same time, the Spanish-speaking parents described their culture as one in which the family is expected to "take care of its own."

Some of the information collected reflects the utilization of vocational and rehabilitative services. Of children in the 18-42 age group, 27% of the disabled individuals receive vocational training and 31% are

enrolled in a sheltered workshop. Of those parents who considered their children old enough to benefit from rehabilitative services, one-half of the parents felt that the Department of Rehabilitation had been somewhat or very helpful. Parents suggested more school counseling about vocational programs and more emphasis on social and employment skills training for their children.

Parents also stressed the need for more information about available vocational services. Many parents were not able to respond to questions about vocational services and appear to need basic information about the types of opportunities and services available to young adults and older developmentally disabled individuals.

PROFESSIONAL INFORMATION

Fifty-seven professional staff who work with developmentally disabled persons completed questionnaires. They represent a variety of work settings, the highest percentage (58%) from Regional Centers. They reported their work as distributed across all age groups of clients, ranging from birth through 65 years.

Ninety-eight percent of professionals who responded to the questionnaire identified language barriers as the most difficult problem confronted by Spanish-speaking parents seeking services for their developmentally disabled children. The next highest rated problems were: lack of information about existing services (84%), transportation (70%), and amount and complexity of paper work (49%). Professionals indicated that parents need services that address many problems, but that language barriers are among the primary problems reducing the effectiveness of parent training, information and referral services, and other needed services.

Like the parents, Spanish-speaking professionals in the service system, particularly those of Hispanic origin, communicate the importance of understanding client behavior related to cultural values that may be different from the dominant culture. They share the concerns of parents for a service system that is responsive to Hispanic clients.

DISCUSSION

Parents and professionals identified the same two problems as the greatest obstacles to obtaining services: language barriers and lack of information. Professionals rated language barriers first; parents rated lack of information first.

Suggestions differed somewhat between parents and professionals related to services that are needed. Parents tended to address specific, discrete types of services such as medical services, and language and physical therapy. Professionals addressed broader changes in the service system. They indicated changes are needed in the way services are delivered, emphasizing that existing services should be made more accessible to the Spanish-speaking community. They suggested that this could be achieved primarily by providing more information in Spanish, more Spanish-speaking service personnel, and service personnel with bicultural understanding. Both parents and professionals suggested the development of training programs that are sensitive to the unique characteristics of Spanish-speaking developmentally disabled clients.

The areas probed in this initial study are complex. Such complexity is represented, for example, by parents who described themselves as "role-bound" in mother/father responsibilities (with mothers largely responsible for child care), but who also attended the Fiesta with their spouse. The high proportion of families in which both parents attended (62%) and actively participated in the Fiesta suggests that the described pattern of exclusive maternal responsibility for children was not a uniform characteristic of these conference participants.

An example with similar implications for cautious data interpretation is represented in the concern for information about services. For the most part, Fiesta parents describe the Hispanic culture as one in which the family is expected to "take care of its own." Thus, they see themselves as reluctant to seek services and information. On the other hand, parents, through both questionnaires and discussions, indicated that lack of available information about services is their largest problem with the service system.

This complexity reflects, in part, the inevitable diversity of factors that contribute to human and social phenomena. It suggests the care and deliberation which should be applied in interpreting the present data, and in drawing actionable conclusions from them. The situations studied in the present inquiry are multiply determined, and may be described in various ways. Where they present problems, these can be conceptualized and addressed by a number of valid approaches.

For example, problems related to communication by Spanish-speaking parents with non-Spanish-

speaking service personnel may be addressed in various ways. One possible solution that represents a traditional response to such a problem is to "increase the number of Spanish-speaking service personnel." Other possible solutions to this problem are the training of Spanish-speaking parents as paraprofessionals in the service system, and increasing the utilization of Spanish-speaking staff for parent and self advocacy training. Such approaches might represent more realistic solutions, given limited resources. These approaches might concurrently address other problems as well. For example, parent paraprofessionals may be more successful than professionals in encouraging other parents to seek and take advantage of services and other opportunities for their children. And parent paraprofessionals may help create a perception of "extended family-ness" in the service system that is consonant with Hispanic cultural values such as "caring for one's own." Many other approaches can be identified as potentially useful, realistic, and effective contributors to eventual "solutions."

The point is simply that the information collected at Fiesta Educativa '80 is both descriptive and limited. Causal relationships, specific recommendations, and firm, actionable conclusions should not be inferred from this type of preliminary data collection effort. Rather, the inquiry should be regarded as an early step toward description and clarification of a community of people and their service needs.

OTHER OBSERVATIONS ON THE INFORMATION-GATHERING EFFORT

1980 was the first year that a large information-gathering effort was undertaken at the Fiesta Educativa. Observations can now be made about the efficiency and effectiveness of the data collection procedures that may be helpful to others undertaking similar inquiry. These observations are detailed in the Final Reports.

Several conference presenters noted that, with each year, the Fiesta participants have become better able to enjoy meaningful involvement in the Fiesta. They have become more proactive participants. The information-gathering may be viewed as a process that can aid parents in better articulating and understanding their needs, as active participants in such efforts.

The information-gathering effort was successful, in part, because of the strong support received from conference presenters. Announcements at morning and afternoon sessions stressed the importance both of completing the questionnaires, and of the broader information-gathering effort. The patience and dedication of the many parents who completed the questionnaire was greatly appreciated. The group discussions, in particular, represented an appropriate and successful component of the information-gathering. Parents used the discussions as an occasion to interact with other parents and with professionals, as well as to exchange feelings and information.

CONCLUSION

Throughout the activities of Fiesta Educativa '80, parents and professionals cooperated to share information and feelings and to enhance important working relationships. Many parents expressed appreciation for a parent program conducted entirely in Spanish, confirming the Fiesta's value as both an outreach and an educational program. The commitment and teamwork of the conference coordinators, staff, and workshop presenters was impressive, and parents as well as professionals appeared to react very positively to the activities.

This year's information gathering represented the first systematic attempt to collect needs data at the Fiesta; it is hoped that the effort contributed something of value to both the process and product outcomes of this exemplary conference.

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INFORMATION GATHERING AT THE FIESTA EDUCATIVA '80

Final Report

Submitted to the

California Department of Rehabilitation

Sponsored by

El Comité Estatal Pro-Fiesta Educativa para Personas con Incapacidades del Desarrollo

EC 15 16 12

INFORMATION GATHERING AT THE
FIESTA EDUCATIVA '80

Final Report

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California Department of Rehabilitation
California Department of Developmental Services

PREFACE

Currently, there is little information available regarding the specific service needs of Spanish-speaking parents of developmentally disabled children. Available data do indicate, however, that many existing services for the developmentally disabled are underutilized by the Spanish-speaking population. Although a combination of factors probably contribute to this pattern of underuse, many social service professionals believe that language barriers are a major factor. To some, agencies that serve the Spanish-speaking population appear inadequately staffed to respond to the communication needs of their clients. Lack of sensitivity to cultural and linguistic factors that affect client needs may be a concomitant of this problem (Marion, 1980). These factors suggest the complex interactions that language differences may represent in practice.

The Spanish-speaking population in California is growing at a rapid rate (U.S. Bureau of the Census, 1980a,b). As the population increases, so does the need to provide adequate and appropriate services for developmentally disabled Spanish-speaking clients. Individuals who are both developmentally disabled and non-English speaking may require special services, particularly when they are also members of low income families (Chan, 1980). A first step toward increasing or enhancing service system responsiveness is to obtain accurate information about this population, their perceived needs, and major problems.

Fiesta Educativa '80 provided an excellent opportunity to collect such information from parents, and from the professionals who work with them. Information about the perceived needs and priorities of these parents should be of interest and utility to a number of audiences.

Funding for information gathering at Fiesta Educativa '80 was provided by the California Departments of Developmental Services and Rehabilitation. Personnel and additional resources were also provided by the Eastern Los Angeles, Harbor, Lanterman, Western, and San Gabriel Regional Centers; the Department of Rehabilitation; and the El Centro Mental Health Center.

We gratefully acknowledge the involvement and support of many skilled and caring people in this effort. Irene Martinez has been invaluable as our primary liaison with the Inter-Regional Center Committee. Victor Franco and Karen Brown also provided continuing assistance in our liaison with the IRC and the many professionals who volunteered to help with information collection.

A number of SWRL staff were essential to the information gathering effort. Judy Larson contributed greatly to the design and conduct of training for all information collection personnel. Andrea Greene's excellent work resulted in the initial draft of this report. Important contributions were also made by Rowell Greene and David Snow on training, and Luis Orozco on translation and development in Spanish. Victor Rodriguez was of continuing support and assistance throughout the effort. Gwen Kaub and Marilyn Poupard provided the finest secretarial support and gave of themselves in countless other ways that make a difference.

Many dedicated professionals also contributed their time in assisting with the information collection effort at the Fiesta. These people are listed on the following page. Most important were the many parents and professionals whose interest and cooperation in providing information made this effort possible.

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INTRODUCTION

Fiesta Educativa '80 was the third annual conference designed specifically for Spanish-speaking parents of developmentally disabled individuals in California. The Fiesta, sponsored by the Comité Estatal Pro Fiesta Educativa, was planned in cooperation with the Los Angeles County Inter-Regional Center Committee (IRC) for the Spanish speaking. Funding for the conference was provided by the California Department of Rehabilitation (DR) and the Department of Developmental Services (DDS).

Fiesta Educativa addressed two general purposes:

1) to provide Spanish-speaking parents of developmentally disabled persons with useful information about available programs and services; and

2) to provide these parents with an opportunity to share, in their own language, their experiences and concerns with other parents and professionals.

The specific goals of Fiesta Educativa '80 included:

1) to provide education and information;

2) to conduct information collection, analysis, and reporting;

3) to provide training experiences for professionals and para-professionals;

4) to encourage and facilitate the formation of local parent support groups; and

5) to increase public awareness of the needs of Spanish-speaking persons with developmental disabilities.

These goals were promoted through a variety of workshops, seminars, small group discussions, information booths, and display centers. More than 1,000 parents and professionals attended the Fiesta, which was held on July 26, 1980. The majority of participants were from Los Angeles

County, although many persons attended from other parts of California, as well as from Arizona, New Mexico, and Texas. Most of the pre-conference publicity for the Fiesta was disseminated through the Regional Centers, and most of the participants were familiar with California's Regional Center system.

Purpose of the Information Gathering Effort

Fiesta Educativa '80 provided a rare opportunity to obtain information about the specific needs of the Spanish-speaking community related to services for the developmentally disabled. Currently, such information appears scant and impressionistic (Birman, 1979). Existing data do suggest that services for the developmentally disabled are underutilized by the Spanish-speaking population (Chan, 1980; Delgado, 1980; Serrano, 1980). Agencies attempting to plan and provide responsive services for this group require accurate information about the characteristics of this group, and perceptions of their service-related needs.

Needs sensing activities conducted by SWRL Educational Research and Development at the Fiesta yielded such information, particularly related to individuals in the Los Angeles area. The information was collected through three different methods.

1. Questionnaires. Two questionnaires were used for data collection: one for parents and one for professionals. Questionnaires were included in each participant's registration packet, and were available in both Spanish and English.

2. Small Group Discussions. Small group discussions on service needs were conducted in Spanish by trained group leaders. The group leaders maintained focus on five central discussion questions, but also provided for the open communication needed by participants to express more fully their needs and experiences. Each group discussion was also attended by a trained recorder who documented the comments made and needs identified by parents

during the sessions. They included questions about the characteristics of the developmentally disabled client, parent knowledge and attitudes, and major service needs and problems as perceived by parents and professionals.

3. Discussion Booths. Two to four discussion booths operated during the entire day, staffed by trained personnel representing the Regional Centers and other social service agencies. These booths were designed to provide conference participants an opportunity to discuss their needs in a "private," individual setting. Discussion booth staff also assisted parents who had questions or difficulty in completing their questionnaires.

Target Audiences for Needs Sensing Report

Two reports of needs have been prepared--one for the California Department of Developmental Services, and one for the Department of Rehabilitation. These reports are intended, in part, to provide the agencies that funded the Fiesta with the needs information of particular interest to them. An Executive Summary has also been prepared.

How to Read This Report

The remainder of this report is divided into three major sections: Methodology, Results, and Discussion. The contents of each section are briefly described here so that those interested in particular aspects of the report may read selectively.

The Methodology section describes the planning and implementation of the information gathering/needs sensing study, and the analysis of the data. The Results section details the frequency of responses to items on the Parent and Professional Questionnaires, and is presented in three parts: Parent Information, Vocational Education and Services, and Professional Information. Cross-tabulation data are included for responses to which certain groups of respondents answered differently from other groups. In addition, discussion group and discussion booth summary information is included throughout, to elaborate questionnaire results.

The Discussion section summarizes parent and professional responses, and compares the perceptions of these two groups regarding needed services. Observations and some interpretations related to the information gathering effort are also presented in the Discussion. The appendices include further background information and documentation, such as copies of the data collection instruments and recording forms.

METHODOLOGY

Chronology of Needs Assessment Study

The initial request to conduct a needs sensing study at Fiesta Educativa '80 was made to SWRL by the Inter-Regional Center Committee. During November and December, 1979, SWRL staff members met with the IRC Committee to obtain information about the desired scope and purpose of the information gathering effort. The three methods of data collection were planned, and a prospectus describing information gathering activities was submitted to the IRC Committee in December of 1979. The prospectus was reviewed and approved by the Committee, and by representatives of the Departments of Developmental Services and Rehabilitation.

Instrument Development. In May, 1980, a content plan was prepared by the SWRL staff that detailed the type of information to be collected in the needs sensing activity. (The content plan is presented in Appendix A.) Data collection instruments were designed from this content plan to obtain information about client characteristics, parent knowledge and attitudes, obstacles to obtaining services, and new service needs. The three data collection methods were designed so that, used together, they addressed the desired information areas. (Data collection instruments are presented in Appendix B.)

The content plan and instruments were reviewed by the IRC Committee, Fiesta Planning Committee, and DDS and DR representatives. Questions of particular interest to the Department of Rehabilitation were suggested and added to the parent questionnaire. Subsequent to approval by all reviewers, the questionnaires and related data collection forms were

produced by SWRL. Data collection methods included small group discussions, parent and professional questionnaires (available in both Spanish and English), and discussion booths. These methods were described in an earlier section of this report under "Purpose of the Information Gathering Effort."

Training of Interviewers. SWRL designed and conducted training for the Fiesta data collection staff. A series of three one-half day training sessions were held one week before the Fiesta. On the first day, discussion group leaders and recorders were trained. Each group leader and recorder attended a half-day training session. Participants were oriented to the purpose of the information collection effort, and to the materials and procedures designed to help them with their responsibilities. They practiced using these materials and procedures in instructional role-playing activities.

On the second day of training, discussion booth personnel were similarly prepared for their tasks. All data collection staff received a set of guidelines for carrying out their functions, and practiced those functions during the training sessions. The guidelines were later used at the Fiesta, to assist the staff in conducting the information-gathering activity for which they were responsible. (Copies of training materials are included in Appendix C.)

The Day of the Fiesta. During the Fiesta the information-gathering activities were described during the first general session, at the start of the day's schedule. Participants were encouraged to complete the questionnaires from their conference packets. Parents who had questions about how to complete the questionnaires were directed to the discussion booths for assistance. Parents who had not yet enrolled in

small group discussions had another opportunity to do so. Two to four discussion booths operated continuously during the day, and five small group discussions were conducted.

Data Analysis. Questionnaire data collected at the Fiesta Educativa were analyzed using simple descriptive techniques, including frequency counts and cross-tabulations. Data from the parent and professional questionnaires were coded and formatted for computer analysis. Responses to closed-end questions (i.e., questions which could be answered by selecting and checking a box) were analyzed by frequency counts and converted to percentages. Responses to open-end questions (i.e., questions for which respondents had to write out an answer) were reviewed by SWRL staff, and major response category descriptors were identifed for each item. (The coding categories are described in Appendix D.) Responses were coded for computer analysis by the descriptor to which they most closely related. For example, for the question "What new service or type of help would be most beneficial to you in caring for your child?" response descriptors included the following: physical therapy services, more bilingual services, more parent training, and more transportation services.

Group discussion data documented by recorders were summarized under five categories, corresponding to the five questions around which the discussions were structured. These summaries were submitted to SWRL staff for analysis and reporting. Comments from the group discussions are included in this report to provide elaboration on the less detailed information obtained through the questionnaires. No statistical analyses were performed on group discussion data.

A draft of the report was prepared and submitted to the IRC Committee for review on September 10, 1980. The final version of this report reflects revisions and refinements, based on reviewer comments and suggestions.

The results of the data collection efforts are described in the next section of this report.

RESULTS

Results of the information gathering activities are presented by the following categories:

Part I. Parent Information

- A. Description of child and family
- B. Parents' perceived needs, problems, and suggestions
- C. Parent attitudes

Part II. Vocational Education and Services

Part III. Professional Information

- A. Description of professionals and clients
- B. Professionals' view of parent needs

Within each category, results are presented first from the questionnaire items in that category; these are followed by information from the group discussions.

Responses to items on the Parent Questionnaire are reported in the Parent Information subsection of this report. Responses to each item reported are presented along with the specific item as stated on the questionnaire.

A total of 317 questionnaires were returned by Fiesta parents in time for inclusion in this report. Many couples attended the Fiesta, and in some cases a single questionnaire was completed jointly, by both husband and wife. Thus, the questionnaires represent the input of more than 317 parents.

Cross-tabulations were performed for each descriptive variable on the parent questionnaire so that interactions between two variables could be observed. These data indicate whether a particular group of parents responded differently from other groups. Where large differences in responses among groups were identified through the cross-tabulations, these differences are reported in the Results section.

Information from the small group discussions and summary comments by discussion booth staff are also included in the Results section. The discussion group and discussion booth data are qualitative and anecdotal in nature; they are used to provide detail and elaboration on the questionnaire data.

Part I: Parent Information

A. Description of Child and Family

Questionnaire Item:

My developmentally disabled child's age is ____ .

Results:

Age Groups of Handicapped Children

Age in Years	No. Children in Group	%
Under 6	85	30.7%
6-11	64	23.1
12-17	64	23.1
18-21	31	11.1
22-42	33	11.9
Total All Ages	277	100

The majority of parents attending the Fiesta had developmentally disabled children. Only 12% of parents reported that their children were adults over the age of 21.

Questionnaire Item:

My child is ☐ male ☐ female

Results:

Sex of Child (n=305)

Sex	%
Male	57%
Female	43

Questionnaire Item:

His/her disability is (mark every appropriate square)

- ☐ mental retardation
- ☐ Down's syndrome (mongolism)
- ☐ physical handicap
- ☐ speech and language disorder
- ☐ epilepsy
- ☐ cerebral palsy
- ☐ autism
- ☐ other (describe) _____
- ☐ don't know

Results:

Parents' Perceptions of Child's Disabilities (n=316)

Disability	% Parents[a]
Mental Retardation	45.9
Speech or Language Disorder	28.2
Down's Syndrome	21.8
Cerebral Palsy	15.2
Epilepsy	14.9
Physical Handicap	12.7
Hyperactivity	5.4
Autism	2.8
Slow Learner	1.6

[a]Percentages total more than 100 because parents were encouraged to check every appropriate diagnosis.

Questionnaire Item:

His/her disability is considered to be

- ☐ mild
- ☐ moderate
- ☐ severe

Results: The following table shows the child's diagnosis by the severity of the disability. For purposes of this table each child was assigned a single disability.

Percent Parent Responses to Type and Severity of Their Children's Disability (n=294)

Disability	% Mild	% Moderate	% Severe	% Total
Mental Retardation	16.7	35.4	16.3	68.4
Physical Disability	.7	2.0	1.4	4.1
Language Disorder	3.7	3.4	2.0	9.2
Cerebral Palsy	--	5.1	6.1	11.2
Epilepsy	1.0	.7	--	1.7
Autism	--	1.0	.7	1.7
Hyperactive	--	1.0	.3	1.4
Not Sure	1.0	1.0	.3	2.7
Total	23	50	27	100

Questionnaire Item:

Which regional center is your child registered with?

Results:

Parent Attendance by Regional Centers (n=317)

Regional Center	No. of Parents	% of Total Attendance
Eastern Los Angeles	51	20.2
North Los Angeles County	40	15.8
Lanterman	34	13.4
South Central Los Angeles	23	9.1
San Gabriel Valley	21	8.3
Harbor	19	7.5
Western	18	7.1
San Diego	14	5.5
Tri-Counties	10	4.0
Golden Gate	6	2.4
Orange County	6	2.4
Valley Mountain	5	2.0
Central Valley	3	1.2
Kern	2	.8
Alta California	1	.4
No Regional Center affiliation reported	64	20.0
Total	317	100

Parents from four additional regional centers attended and participated in Fiesta activities, but were not represented in the questionnaire data. These Centers include: Inland Counties Developmental Disabilities Services, North Bay Regional Center, Regional Center of the East Bay, and the San Andreas Regional Center. Parents attending the Fiesta represented all but two of California's 21 Regional Centers.

Questionnaire item:

Number of other children at home _____.

Results:

Number of Other Children (n=278)

Number of Children	Parents Responding
No other children	24
1	55
2	56
3	62
4	35
5	21
6	12
7	6
8	7

Questionnaire item:

Are there other people in your family who need social or medical services?

☐ yes ☐ no ☐ not sure

Results:

Percent Other Family Members Needing Services (n=291)

Yes	19
No	72
Not sure	9

Questionnaire Item:

Did your husband/wife attend the Fiesta?

☐ not married ☐ yes ☐ no (reason) _____

Results:

Spouse Attendance (n=297)	
Yes	58%
No	32%
Not married	10%

Questionnaire Item:

I have been in meetings where an Individualized Education Plan (IEP) was prepared for my child.

☐ yes, I have attended an IEP meeting
☐ no, I haven't attended an IEP meeting
☐ I don't know what an IEP is

Results:

Percent Parents Attending IEP Meeting (n=300)

Response	Parents of all Children	Parents of School-Age Children (6-17 yrs.)
Yes	44%	55%
No	15	13
Don't know what an IEP is	41	32

NOTE: Over half of the parents of school-age children have attended an IEP meeting. However, almost one-third of this group do not know what an IEP is.

Questionnaire Item:

How much training have you had in the past two years that was designed for parents of disabled children?

- ☐ a lot (more than 5 parent education programs)
- ☐ some (2 to 4 parent education programs)
- ☐ very little (1 parent education program)
- ☐ I have never had any parent training or education other than this Fiesta

Results:

Percent Parents With Training in Past Two Years (n=299)

More than 5	13%
2 to 4	17
1	11
No parent training	59

NOTE: Fewer than one-third of the parents have attended two or more parent training programs, and 70% have had very little training or no training besides the Fiesta. These results indicate the need for such educational events. They suggest, in part, that training programs for parents of disabled children are lacking, or are not easily accessible to the Spanish-speaking community.

Questionnaire Item:

Are you a member of a parent group or advocacy group that helps people who have disabilities?

- ☐ yes (what group)? _____
- ☐ no
- ☐ not sure

Results:

Percent Parents in Advocacy Group (n=295)

Yes	33%
No	62
Not sure	5

NOTE: These results also suggest, in part, a lack of availability or accessibility of parent groups. Cross-tabulation of this item with age of child indicated that of the parents who have a disabled child age 22-42, 52% belong to a parent or advocacy group.

In addition to descriptive data collected on the parent questionnaire, one of the small group discussion questions yielded descriptive information about the Spanish-speaking community. Parents were asked, "What special characteristics of the Spanish-speaking community/family need to be understood by people who provide services for the developmentally disabled?"

Responses to this question included the following:

- Maybe they have to understand how we had to deal with the problems on our own in Mexico.
- I was told to put my daughter on birth control pills. No consideration was given to my culture or to my ability as a mother to act as counselor or give advice to my daughter.
- Latins are timid--there is a feeling of intimidation about seeking out services.
- Placement is difficult for me to talk about . . . because of our "Latin" culture . . . We want to care for our own children instead of placing them.
- We are devalued--our children are considered stupid, whether disabled or not.
- There is a general lack of respect, communication, and sensitivity toward the Spanish-speaking community. Much of this seems to be based on language problems.

These comments suggest some factors that may contribute to the problems Spanish-speaking parents have in obtaining what they consider appropriate, responsive services for their children.

B. Parents' Perceived Needs, Problems, and Suggestions

Questionnaire Item:

In the last two years, what have been your biggest problems related to services for your child? (Think about all types of medical, educational, vocational, social, and other services. Check all that apply.)

- ☐ Agency staff couldn't speak Spanish
- ☐ Too much paper work
- ☐ Agency staff seemed prejudiced against Spanish-speaking people
- ☐ Agency too slow
- ☐ Lack of cooperation from professionals
- ☐ Lack of information about existing services
- ☐ Services too expensive
- ☐ Needed services not available
- ☐ Lack of transportation
- ☐ Other (describe) _____

Results:

Parents' Perceptions of Their Biggest Problems in Obtaining Services (n=316)

Problem	Percent[a]
Lack of information about existing services	29%
Agency staff couldn't speak Spanish	17
Lack of transportation	17
Agency too slow	16
Lack of cooperation from professionals	16
Too much paper work	15
Needed services not available	10
Agency staff seemed prejudiced against Spanish-speaking people	7
Services too expensive	6
Other: I have to do everything myself	6

[a]Percentages total more than 100 because parents were encouraged to check all applicable problems.

Cross-tabulations of each of these problems with age of disabled child show that some problems are more prevalent among parents of children in certain age groups. For example:

- 55% of parents of children ages 22-42 years checked #1--Lack of information. This is the highest percentage of any group, and suggests that lack of information may be a particularly serious problems among parents of older children.

- Only 2% of parents with children under 6 years checked #7--"Needed services not available." This suggests, in part, that services for very young children may be more adequate and accessible than those for older children.

Information about service-related problems was also provided in the small group discussions. Parents were asked, "What specific kinds of problems have you experienced that prevented you from receiving available services?"

Group discussion responses to this question may be summarized in the following categories:

- requirements to fill out complicated forms in English
- inability to communicate with English-speaking staff
- long waits to receive services that are needed immediately
- problems getting transportation to service agencies
- general problems obtaining accurate information about where to go and how to get services appropriate for the child
- services not publicized in Spanish
- problems accessing child's diagnostic and medical records

Questionnaire item:

What new service or type of help would be most beneficial to you in caring for your child? _____

Results:

Most Frequently Requested New Services

Type of Service	% Parents Requesting Service
More medical services	17%
More speech therapy	13
Better educational programs	12
More physical therapy	9
More respite and child care services	9
More parent training	6

Cross-tabulation of this item with child's age showed that, of those who suggested parent training, 64% had a child under 6 years.

Other suggestions made by parents about new services included the following:

- better evaluation of child's condition
- better psychiatric services
- more information on child's development
- Spanish-speaking staff to provide therapy and services
- educational services more specific to child's needs
- child care while parents work
- child care closer to parents' homes

Two of the small group discussion questions related to services. One was, "How would you change the services that are now available, or what new services or programs would you add, in order to better meet your child's needs and your own?"

This question stimulated a great deal of discussion. Among the most common suggestions about services and programs were the following:

- educational programs taught in Spanish for developmentally disabled children
- parent education about how to be advocates for their children and how to learn more about children's disabilities
- more parent groups for sharing and interaction
- better transportation services
- respite and child care for both disabled children and other children in family so that parents can attend appointments
- more Spanish-speaking service personnel
- more diagnostic centers that are close to parents' homes
- "better trained" and "more considerate" personnel at Social Security offices
- special bus services for disabled individuals

Another small group discussion question related to needed services was, "What kind of non-vocational training should developmentally disabled persons receive in order to make them more independent?"

Frequent parent responses to this question include the following:

- teach the disabled children personal care skills such as dressing and toilet training
- teach better basic academic skills
- teach parents and families how to encourage independence in the disabled person, because we tend to be overprotective
- offer sex education for developmentally disabled people

Questionnaire Items:

What have you worried most about this year for your child?

What do you worry most about for your child's future (when he/she is an adult)?

Results:

Comparison of Concerns Parents Have Now and Concerns for Future About Their Children

Concern	Present Concern %	Rank	Future Concern %	Rank
Inadequate speech therapy	19.5	1	3.0	8
Inadequate medical care	14.6	2	3.4	7
Inadequate educational services	12.4	3	2.6	9
Behavior and social skills	10.2	4	6.0	4
Inadequate physical therapy	8.0	5	1.7	11
Permanence of disability	6.2	6	6.8	3
Self-care skills and training	5.8	7	29.5	1
Inadequate child respite care	3.1	8	4.7	6
Services after age 21	2.7	9	2.1	10
Care after parents' death	2.7	9	17.9	2
Better social service staff	2.2	10	.9	13
Inadequate residential services	1.3	11	3.0	8
Inadequate bilingual services	.9	12	--	--
Inadequate transportation	.9	12	--	--
Inadequate parent training	.9	12	--	--
Inadequate assessment services	.9	12	--	--
Inadequate services for undocumented clients	.9	12	1.3	12
Employment/work	.9	12	6.8	3
Sex awareness for adolescents	.4	13	1.3	12
Inadequate information and referral services	.4	13	.3	14
Inadequate recreation opportunities	.4	13	.4	14
General concern about the future	--	--	5.6	5
Inadequate financial resources	--	--	1.7	11
Inadequate service in general	.4	13	.9	13
Total	100 n=226		100 n=234	

Parents' present concerns focused on their child's inability to walk, see, talk, and hear. They expressed uncertainty about their child's diagnosis and potential, and about getting services appropriate to the disability. Similar types of worries and concerns were expressed by parents in the small group discussions.

Cross-tabulations of the parents' future concerns with the age of their child revealed that many of these concerns are most prevalent among parents of children in certain age groups. For example:

- 67% of the parents who said they were worried about the permanence of the disability have a child under six years;
- 67% of the parents who have a child 6-11 years and 54% of the parents who have a child under six years said ability to care for him/herself is their greatest worry;
- By the time a child is 12 years old, the parents' major concern for the future is the child's care after the parents' death.

It appears that parents of young children (up to about age 12) are most concerned with defining their child's disability, the permanence of the disability and the extent of language and physical impairment. Parents begin to worry when their children are still quite young (from age 12) about the child's adult functioning (self-care skills and employment), and about what will happen to the child after the parents are deceased.

C. Parent Attitudes

Questionnaire Item:

Is you child able to use public transportation?

☐ yes ☐ no ☐ too young

Results:

Percent Children Able to Use Public Transporation (n=288)	
Yes	16
No	50
Too young	34

NOTE: Although this low percentage may appear to reflect a protective parent attitude, many factors besides parent attitude and child age may inhibit the use of public transportation by developmentally disabled individuals. For example, learning to use a public transportation system in a large metropolitan area like Los Angeles is an extremely complicated process for many disabled people. In addition, many physical disabilities may make use of public transportation extremely difficult or impossible.

Questionnaire Item:

From time to time, I would like to have a qualified person take care of my child for a day or two.

- ☐ yes
- ☐ no
- ☐ not sure

Results:

Respite Care	
Yes	62%
No	21%
Not sure	18%

NOTE: Responses to this item reflect a high perceived need for respite services. The "yes" response was not unique to a particular group; parents of children of all ages with all severities of disabilities indicated they would like occasional child care assistance. This response also suggests parent willingness to trust their children's care to a qualified person outside the home.

Questionnaire Item:

Sex education in school is

- ☐ appropriate for my child
- ☐ not appropriate for my child
- ☐ not sure

Results:

Sex Education	
Appropriate for my child	25%
Inappropriate for my child	14%
Not sure	61%

NOTE: The high percentage of "not sure" responses suggests a general uncertainty about sex education. This is a controversial topic in all types of educational settings, and seems particularly sensitive in the education of the developmentally disabled. This response may suggest, in part, need for both parent training related to the sex education of their disabled child, and also for parent workshop sessions, in which values and attitudes toward sex and sex education can be explored and clarified.

Questionnaire item:

When my disabled child becomes an adult, he/she will

- ☐ probably live at home
- ☐ probably not live at home
- ☐ not sure

Results:

Parent Attitude Toward Independent Living

Probably live at home	65%
Probably not live at home	7%
Not sure	28%

NOTE: This item was cross-tabulated with severity of the handicap (mild, moderate, severe). Of the parents whose children are mildly disabled, 74% said their children would probably live at home. This was a higher percentage than parents of moderately and severely disabled children, who indicated 62% and 61% respectively.

Questionnaire item:

When my child becomes an adult, he/she will

- ☐ probably have a job
- ☐ probably not be able to have a job
- ☐ not sure

Results:

Parent Attitude Toward Employment

Probably have a job	29%
Probably not have a job	22%
Not sure	50%

NOTE: The high percentage of parents who were not sure about this item may suggest that parents do not have sufficient information about the types of jobs available to and appropriate for their children. As might be expected, parents who characterize their children as mildly disabled represent the highest percentage of positive responses to this item.

Questionnaire Item:

How helpful has the Regional Center for the Developmentally Disabled been for you and your child?

- ☐ very helpful
- ☐ somewhat helpful
- ☐ not helpful

Results:

Attitude Toward the Regional Center

Very helpful	50%
Somewhat helpful	39%
Not helpful	11%

The small group discussions and the summaries of parent comments written by discussion booth staff yielded additional information about parent attitudes. Some of the major categories of comments related to attitudes are summarized below.

- Spanish-speaking parents are not accustomed to being active information seekers, especially in a society in which they feel isolated from the mainstream. They perceive that society in general "does not understand or respect their culture." This is magnified by the language barrier.

- Parents are accustomed to "caring for their own," and thus are extremely appreciative of any services they receive.

- Particularly in older families, the mother is considered to have primary responsibility for caring for the disabled child. Fathers are not expected to contribute to child care. (The large number of families represented by both parents at the Fiesta does not reflect the pattern of maternal responsibility for child care. Some professionals have suggested that this pattern may be changing in "younger" families.)

- Parents seemed to be stimulated to take a more active role in obtaining information and services during Fiesta activities. The mingling of parents and professionals as partners in the Fiesta proceedings may contribute to parent information-seeking and involvement which carries over to other activities and situations.

Part II: Vocational Education and Services

Both the questionnaire and the group discussions provided information related to vocational training and status. This section of the report presents those results, focusing particularly on the parents who stated their children were 18 years of age or older.

Questionnaire Item:

Is your child receiving pre-vocational education (preparation for job training)?

☐ yes ☐ no

Results:

Percent Receiving Pre-Vocational Education (n=177)

Age Group	Number in Age Group	% Yes Within Age Group	% No Within Age Group
6 through 11	56	2	98
12 through 17	60	22	78
18 through 21	30	53	47
22 through 42	31	35	64

Questionnaire Item:

Is your child receiving vocational education (job training)?

☐ yes ☐ no

Results:

Percent Receiving Vocational Education

Age Group	Number in Age Group	% Yes Within Age Group	% No Within Age Group
12 through 17	58	6	52
18 through 21	29	8	21
22 through 42	30	8	22

Questionnaire Item:

If your child is receiving or has received some type of job training, how would you describe the program?

- ☐ good preparation for work
- ☐ fair
- ☐ poor--did not meet my child's needs

Results:

Quality of Job Training

Age Group	Number in Age Group	% Good Within Age Group	% Fair Within Age Group	% Poor Within Age Group
12 through 17	12	0	7	5
18 through 21	16	4	6	6
22 through 42	23	5	6	12

Questionnaire Item:

Is your child presently working at some type of sheltered workshop or special job?

☐ yes ☐ no

Results:

Percent Participating in Sheltered Workshop

Age Group	Number in Age Group	% Yes Within Age Group	% No Within Age Group
12 through 17	55	0	55
18 through 21	27	6	21
22 through 42	31	14	17

Questionnaire item:

Is your child presently working at a regular job?

☐ yes ☐ no

Results:

Percent of Clients Working

Age Group	Number in Age Group	% Yes Within Age Group	% No Within Age Group
12 through 17	52	2	98
18 through 21	27	7	93
22 through 42	28	4	96

Questionnaire item:

How helpful has the Department of Rehabilitation (vocational rehabilitation) been for you and your child?

☐ very helpful
☐ somewhat helpful
☐ not helpful
☐ my child is too young

Results:

Parents' Attitude Toward the Department of Rehabilitation (n=117)

	Response			
Child's Age	Very Helpful	Somewhat Helpful	Not Helpful	Child too Young
12 through 17	23	11	32	34
18 through 21	13	23	60	3
22 through 42	25	36	39	--

The discussion groups and discussion booths also yielded information related to vocational education. Many comments were made that are important to understanding parents' problems and attitudes when helping their children move toward successful employment.

Parents made many comments that identified the elements they regard as important in a quality vocational program. Some were general, and applied to developmentally disabled individuals. Other comments were stated in terms of the parent's own child. For example:

- Take into consideration what the developmentally disabled like to do, so that they may work with joy.
- Provide school counseling about vocational training.
- Teach disabled persons to enjoy work and to derive personal satisfaction from it.
- Training for dd adults should include more individual attention to the person's needs.
- Provide social training and development skills so that disabled persons can function more normally.
- Provide the disabled individual with a better understanding of his/her potential in the workplace.
- He needs to learn to make friends and be more outgoing. He needs some kind of social training to help him work.
- [My daughter] would like a workshop where clients are closer to her age.
- If people's attitudes change, it would be easier for disabled persons to lead a more normal and productive life.
- It is important that all the developmentally disabled have some work--something to do according to their abilities.

Parents most frequently stated that lack of adequate information was their biggest problem in caring for their child. This problem was also

clearly expressed in relation to vocational services. The following were typical comments:

- Latins are often timid and, therefore, the counselor should make sure that the parents and clients are provided with thorough information on what steps to take and what the alternatives are when seeking services.
- It would be good if more pamphlets were available which indicated current services that are available.
- Send out pamphlets on a yearly basis.
- Regular groups for parents so they may be able to obtain more information.
- It is very important that parents receive ongoing training relative to developmental disabilities so that they can relate to their handicapped child in a more normalizing manner.
- We need more information and pamphlets in Spanish.

Cultural values and beliefs were also mentioned by parents as important considerations when providing vocational services. The following statements were among those made during the group discussions:

- No consideration was given to my culture or to my ability as a mother to act as counselor or give advice to my daughter. No respect was given to my way of thinking. We should be given the opportunity to teach our children what is right and what is wrong.
- I have learned that it is because of our "Latino" culture that we want to care for our own children instead of placing them.
- Because I don't believe in letting other people take care of her or I don't trust them somehow, I've been my own preventer of receiving available services.
- She is just an innocent child . . . that is one of the reasons I want her to be with me so I can take care of her.

Part III: Professional Information

Professional Questionnaires were completed by 57 professional staff who attended the Fiesta. Results from the Professional Questionnaire are presented in this section.

A. Description of Professionals and Clients

Questionnaire Item:

Which of the following is your primary work setting?

- ☐ school
- ☐ hospital
- ☐ vocational rehabilitation
- ☐ regional center
- ☐ other (specify) _____

Results:

Professionals' Primary Work Setting (n=57)

Location	% of Professionals
Regional center	58%
Other	14
School	21
Vocational rehabilitation	5
Hospital	2

Questionnaire Item:

How old are most of your clients?

- ☐ 5 years or under
- ☐ 6-12
- ☐ 12-18
- ☐ 18-25
- ☐ 25-45
- ☐ 45-65
- ☐ 65 or over

Results:

Ages of Clients Served by Professionals (n=57)

Age	Percent
5 years or under	14%
6-12	12
12-18	7
18-25	7
25-45	7
45-65	2
65 or over	0
Multiple age groups	32

B. Professionals' View of Parent Needs

Questionnaire Item:

What do you consider to be the most difficult problem(s) confronted by Spanish-speaking people when they attempt to obtain services (e.g., medical, educational, vocational, social) for their developmentally disabled children? Check all that apply.

- ☐ language barriers
- ☐ transportation problems
- ☐ amount and complexity of paper work
- ☐ high cost of services
- ☐ lack of information about existing services
- ☐ needed services not available
- ☐ slow processing by service agency
- ☐ other (specify) _____

Results:

Professionals' Estimates by Percent of the Problems Faced by Spanish-Speaking People Who Seek Service (n=57)

Problem	Percent
Language barriers	98%
Lack of information about existing services	84
Transportation problems	70
Paper work: amount and complexity	49
Slow service agency processing	32
High cost of services	32
Needed services not available	28
Undocumented status of many potential recipients	5
The fact that parents must do all work if their child is to receive any services	5

Questionnaire Item:

What new services or changes in existing services do you feel are most needed by Spanish-speaking, developmentally disabled persons and their families? (Please describe below.)

Results:

Percentage of Professionals Who Felt New Services Were Needed or Existing Services Should Be Changed (n=49)

Service	Percent
Bilingual services	46%
Information and referral	14
Parent education and training	11
Educational services	9
Medical services	5
Respite and child care	5
Transportation	5
More services needed generally	2.3
Better staffing of all services	2.3
School or other programs for over 21	2.3
Family counseling services	2.3

NOTE: Professionals completing the questionnaire were most concerned with the adequacy and responsiveness of existing bilingual services. Some of the specific comments and suggestions made by the professionals related to new services are presented below:

- good translations of forms and more Spanish-speaking professionals
- trained bilingual teachers for special education classes
- current information and media advertisement of services available in Spanish

- more bilingual foster and respite care placements
- Spanish-speaking administrators in policy-making positions
- more pamphlets and reading material in Spanish
- parent education programs in Spanish (particular emphasis was placed on education related to child development, and to information regarding "normal" and "abnormal" development)
- sensitivity to Hispanic cultures
- better programs for learning disabled

DISCUSSION

This study was designed to provide information about the perceived service needs of Spanish-speaking parents of developmentally disabled children. Data were obtained during Fiesta Educativa '80, an annual parent conference sponsored by the Comité Estatal Pro Fiesta Educativa and funded by the California Departments of Developmental Services and Rehabilitation. Three data collection methods were employed: parent and professional questionnaires, small group discussions, and discussion booth interviews. Reports of the study were prepared for the California Departments of Developmental Services and Rehabilitation.

This section of the report summarizes and then discusses the parent and professional information collected. In addition, retrospective observations of the information gathering effort are presented, along with recommendations for the methodology and focus of continued inquiry in the area.

Parent Summary

Parent Characteristics--Questionnaire Data. Three-hundred seventeen parents completed questionnaires. The median age of their developmentally disabled children was eight years; their age ranged from three months through 42 years. The most common disability reported was mental retardation (46%). Fifty percent of the parents rated their child's disability as moderate, 23% as mild, and 27% severe. Seventy-four percent of the children were registered with one of six Regional Centers: Eastern Los Angeles, North Los Angeles, Lanterman, South Central, San Gabriel, and Harbor. The remaining 26% were distributed across nine other Centers in California.

Of the married parents completing the questionnaire, 64% attended the Fiesta with their spouse.

Over half (55%) of parents with school-age children have attended an Individualized Education Plan (IEP) meeting; however, another third of the parents responding to the questionnaire were not familiar with an IEP, and did not recognize the term.

A small proportion of the respondents described themselves as actively involved in parent training or other parent groups. Seventy percent had attended either the Fiesta only, or the Fiesta and one other parent training program. Two-thirds of the parents did not belong to a parent or advocacy group.

Parent Comments--Group Discussion and Questionnaire Data. During group discussions, parents described communication barriers with "Anglo" society that extend far beyond language differences. Such barriers were frequently described in terms of lack of understanding and sensitivity to Hispanic culture.

The Spanish-speaking parents describe their culture as one in which the family is expected to "take care of its own." Thus they feel that, as a group, they are somewhat reluctant to seek services and information.

On the questionnaire, parents rated lack of information about existing services as their biggest problem in obtaining services for their children. This problem was noted by 29% of the respondents. Five other problems received approximately equal ratings (15% to 17%): agency staff couldn't speak Spanish, lack of transportation, agency too slow, lack of cooperation from professionals, and too much paper work. In general, the same types of problems were emphasized by parents in the small group discussions. During these discussions, however, problems related to interacting with

non-Spanish-speaking personnel received more emphasis than on the questionnaires.

Parent concerns about lack of information regarding existing services are reflected in their suggestions for new services. For example, parents expressed concerns about their children's speech and physical development, and about finding appropriate medical and educational programs. They were concerned that their children have inadequate social skills and self-care skills, and they were worried about what will happen to their children after they (the parents) die.

Parents suggested services that correspond to their concerns: more medical, speech and physical therapy, educational programs, and child care services. Similar comments were made by parents on the questionnaires and in the group discussions. Many parents indicated that they lack an adequate understanding of their child's specific disability, development, and potential.

Some of the parent attitudes surveyed relate to their children's autonomy and independence, and to how independent parents feel their children could or should be. A large percentage of parents (62%) said they would like to have respite care services. They were largely unsure (61%) about whether sex education in school was appropriate for their children. Most parents (65%) said their children would probably live at home as adults. Less than one-third (29%) thought their children would have jobs; 50% were not sure. On the whole, then, these parents are skeptical of their children's ability to live or work independently as adults. Parents do seem receptive to the concept of respite care and other family support services such as those offered at the Regional Centers.

Some of the information collected reflects the utilization of vocational and rehabilitative services. Parents report that, of children in the 18-42 age group, 27% of the disabled individuals are receiving vocational training and 31% are enrolled in a sheltered workshop. Most of those over 18 are receiving some type of vocational service. Of those parents who considered their children old enough to benefit from rehabilitative services, one-half of the parents felt that the Department of Rehabilitation had not been helpful; one-half indicated that DR had been somewhat or very helpful. Parents suggested more school counseling about vocational programs and more emphasis on social and employment skills training for their children.

Parents also stressed the need for more information about available vocational services. Many parents were not able to respond to questions about vocational services, and appear to need basic information about the types of opportunities and services that can be available for young adult and older developmentally disabled individuals.

Professional Summary

Fifty-seven professional staff who work with developmentally disabled persons completed questionnaires. They represent a variety of settings, the highest percentage (58%) from Regional Centers. They reported their work as distributed across all age groups of clients, ranging from six months through 65 years.

Ninty-eight percent of professionals who responded to the questionnaire identified language barriers as the most difficult problem confronted by Spanish-speaking parents seeking services for their developmentally disabled children. The next highest rated problems were: lack of information about existing services (84%), transportation (70%), and

amount and complexity of paperwork (49%). Professionals indicated that parents need services that address many problems, but that language barriers are among the primary problems reducing the effectiveness of parent training, information and referral services, and other needed services.

Like the parents, Spanish-speaking professionals in the service system, particularly those of Hispanic origin, communicate the importance of understanding client behavior related to cultural values that may be different from the dominant culture. They share the concerns of parents for a service system that is responsive to Hispanic clients.

Comparison of Parent and Professional Comments

Parents and professionals identified the same two problems as the greatest obstacles to obtaining services: language barriers, and lack of information. Professionals rated language barriers first; parents rated lack of information first.

Suggestions differed somewhat between the two groups related to needed services. Parents tended to address specific, discrete types of services such as medical, speech, and physical therapy. Professionals addressed broader changes in the service system. They indicated changes are needed in the way services are delivered, emphasizing that existing services should be made more accessible to and approachable by the Spanish-speaking community. They suggested that this could be achieved primarily by providing more information in Spanish, more Spanish-speaking service personnel, and service personnel with bicultural understanding. Both groups suggested improved, specialized educational programs that are sensitive to the unique characteristics of Spanish-speaking developmentally disabled clients.

There was a large difference in response percentages between parents and professionals; that is, professionals reported more problems than parents. Professionals appeared more inclined to criticize the service system than parents, and they provided more detail related to identified problems and solutions.

Discussion of Parent and Professional Data

The areas probed in this initial study are complex. The resulting possible statements of "needs" and "solutions" are necessarily interdependent. The data may appear inconsistent if they are reviewed with expectations for simplicity or with preconceived notions about the "appropriate findings" of this study.

There are many instances of such complexity in the data. For example, many parents described themselves as "role-bound" in mother/father responsibilities (with mothers largely responsible for child care), but also attended the Fiesta with their spouse. The high proportion of families in which both parents attended and actively participated in the Fiesta suggests that the described pattern of exclusive maternal responsibility for children was not a uniform characteristic of these conference participants.

An example with similar implications for cautious data interpretation is represented in the concern for information about services. For the most part, Fiesta parents describe the Hispanic culture as one in which the family is expected to "take care of its own." Thus, they see themselves as reluctant to seek services and information. On the other hand, parents through both questionnaires and discussions indicate that lack of available information about services is their largest problem with the service system.

This complexity reflects, in part, the inevitable diversity of factors that contribute to human and social phenomena. It suggests the care and deliberation which should be applied in interpreting the present data, and in drawing actionable conclusions from them. The situations studied in the present inquiry are multiply determined, and may be described in various ways. Where they present problems, these can similarly be conceptualized and addressed by a number of valid approaches.

Many parents attending the Fiesta are minimally involved in other parent groups or parent education activities. Is this because of lack of availability of such programs in Spanish? Because of lack of adequate information dissemination related to such programs? Because existing programs need to be made more accessible to these parents? Or because many Hispanic parents are actually reluctant to seek and join such programs, or to avail themselves of organized parent education services?

Each of these explanations probably contribute to the situation, and taken together they don't account for it entirely. With such respect for the complexity of the phenomena that the Fiesta needs sensing activity addressed, some needs can be tentatively stated and related possible solutions can begin to be explored.

The recurrent problems which emerged from each data collection method employed in the study relate to:

a. the difficulty of Spanish-speaking parents in accessing accurate information about their developmentally disabled children, and about services that are available to them;

b. the difficulty of accessing and utilizing services because of language differences--particularly the problems related to delivery of information in Spanish to parents who speak Spanish exclusively or primarily.

These problems, and possible solutions to these problems, were stated in a limited number of ways in the Fiesta data. For the most part, respondents indicated that too little information for these parents was available, and that services and information were unavailable in Spanish. Solutions recommended by respondents were stated primarily in the related terms of more information for parents, and more Spanish-speaking service personnel.

The perspective on solutions offered by Fiesta participants is a function, in part, of the structure of both the questionnaire items and the questions raised in the group discussions. Subsequent inquiry in this area should refine information-gathering mechanisms to stimulate and support more divergent and varied examination of perceived problems and "possible solutions."

For example, problems related to communication by Spanish-speaking parents with non-Spanish-speaking service personnel may be addressed in a number of ways. One possible solution that represents a traditional response to such a problem is "increase the number of Spanish-speaking service personnel." Other possible solutions to this problem are the training of Spanish-speaking parents as paraprofessionals in the service system, or increasing the utilization of Spanish-speaking staff for parent and self-advocacy training. Such an approach also might represent more realistic solutions, given limited resources. The approach might concurrently address other problems or needs, as well. For example, parent paraprofessionals may be more successful than "professionals" in encouraging other parents to seek and take advantage of services and other opportunities for their children. And parent paraprofessionals may

help create a perception of "extended family-ness" in the service system that is consonant with Hispanic cultural values such as "caring for one's own." Many other approaches can be identified as potentially useful, realistic, and effective contributors to the eventual "solution."

The point is simply that the information collected at Fiesta Educativa '80, and presented in this report, is both descriptive and limited. Causal relationships, specific recommendations, and firm, actionable conclusions should not be inferred from this type of preliminary data collection effort. Rather, the inquiry should be regarded as an important early step toward description and clarification of a community of people and their service needs. Subsequent inquiry can incorporate more specific questions, following, as appropriate, on direction suggested both by the present data and by the agencies sponsoring and supporting the activity.

Further inquiry can help to detail the description presented by the present data. And thoughtful, cooperative effort on the part of the key groups affected by such inquiry--parents, clients, and professionals together--can help to identify the combination of realistic approaches to improving services and opportunities, both formal and informal, for the developmentally disabled.

Retrospective Observations About the Information Gathering

1980 was the first year that a large information-gathering effort was undertaken at the Fiesta Educativa. Observations can now be made about the efficiency and effectiveness of the data collection procedures that may be helpful to others undertaking or extending similar inquiry.

Several conference presenters noted that, with each year, the Fiesta participants have become better able to enjoy meaningful involvement in the Fiesta. They have become more proactive participants. The information

gathering may be viewed, in part, as a process that can aid parents in better articulating and understanding their needs, as active participants in such efforts.

Observations Related to the Questionnaire Methodology. Parents attending the Fiesta demonstrated a desire to complete their questionnaires correctly, and put a great deal of effort into doing so. They obtained assistance when they had difficulty responding to questions, and some parents commented that they were not accustomed to being asked about their needs and concerns.

A primary problem associated with use of the questionnaire was that many parents were unable to complete the items independently. Many parents sought discussion booth personnel for assistance with the questionnaire. If questionnaires are used in future information collection efforts, such assistance to parents in completing questionnaires should be continued. For purposes of data analysis, methods should also be adopted for a) tracking multiple questionnaires from a single family, and b) identifying individual questionnaires that represent the input of two or more family members.

During Fiesta Educativa '80, discussion booth staff were available to assist parents with questionnaires when necessary. They reported several reasons for difficulties in completing the questionnaire. In addition to parents who simply lacked sufficient skill in reading or writing, many parents were reluctant to criticize the service system or were unable to identify specific needs or service delivery problems. Thus, the desirability of alternative and complementary approaches to information gathering, such as group discussions and discussion booths, is suggested.

Alternative approaches may reach those who do not complete a questionnaire, and also provide opportunity for elaboration and personalization of participant responses. A structured interview methodology might also be considered to enhance the total data collection effort.

Another consideration that should receive continued attention in future information collection efforts is the option of completing questionnaires in Spanish or English. Despite efforts to inform them, some parents at Fiesta Educativa '80 were unaware that questionnaires were available in English as well as Spanish. (All parents received questionnaires in Spanish, and could request English-language versions if they preferred them.) The inclusion of both language versions of the questionnaire in each registration packet should be considered.

Future information collection efforts should also consider additional mechanisms for encouraging input from more professionals attending the Fiesta. Many professionals did not complete questionnaires related to their perceptions of service-related needs. Some reported later that they did not understand that the professional questionnaires were directed to them, perhaps because of their involvement as presenters or their earlier role in helping to plan the Fiesta. Clarification of the desirability of needs information from all professionals attending would, in the future, be appropriate.

The use of a parent questionnaire was successful, in part, because of the strong support received from conference presenters. Announcements made at both morning and afternoon sessions stressed the importance of completing the questionnaires, and of the broader information gathering

effort. The patience and dedication of the many parents who completed the questionnaire was greatly appreciated.

Observations Related to the Discussion Booth Methodology. Two factors affected the implementation of data collection at the discussion booths. First, as indicated above, a number of parents had difficulty completing the questionnaire, and they were informed that they could receive assistance at the discussion booths. Discussion booth staff spent most of their time helping these parents complete the questionnaires. Thus, they had little time to collect additional interview information on parent needs, as initially intended. Second, the booths did not provide parents with an adequate opportunity to discuss their needs and concerns in a private setting, on a one-to-one basis. The booths were located in a busy conference display area, and it was difficult to conduct personal interviews that could not be overheard. Thus, the discussion booths did not yield the individual interview information that had been anticipated.

Discussion booth staff prepared summary comments about their responsibilities. They felt that it was important for them to assist the parents in completing the questionnaires. Most parents appreciated the opportunity to express their needs, and put considerable effort into responding appropriately. If a similar combination of methods is used in the future, more valuable interview information might be obtained by having some staff available to help with the questionnaires, and by providing separately staffed, private interview booths.

Observations Related to the Group Discussion Methodology. The group discussions represented an appropriate and successful component

of the information gathering effort. Parents used the discussions as an occasion to interact with other parents and with professionals, as well as to obtain information. The discussions, along with other conference activities, encouraged a high degree of mingling and cooperation between parents and professionals. The skill and commitment of the group discussion leaders was evident, and parents appeared to react very positively to the experience.

The group discussion format encouraged parents to explore their feelings and attitudes about the service system and the client population, and enabled parents to contribute specific and personalized needs information. For both the data they yield and the opportunity they provide to share feelings and experiences, such group discussions appear to be a valuable conference activity.

Conclusion

Throughout the activities of Fiesta Educativa '80, parents and professionals cooperated to share information and feelings and to enhance an important working relationship. Many parents expressed appreciation for a parent program entirely in Spanish, confirming the Fiesta's value as both an outreach and an educational program. The commitment and teamwork of the conference coordinators, staff, and workshop presenters was impressive, and parents as well as professionals appeared to react positively to the activities. This year's information gathering represented the first systematic attempt to collect needs data at the Fiesta, and it is hoped that the effort contributed something of value to both the process and product outcomes of this exemplary conference.

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APPENDICES

Appendix A

This appendix contains the original content plan used in designing the information collection.

CONTENT PLAN FOR FIESTA EDUCATIVA

The purpose of this content plan is to define the information to be obtained at the Fiesta Educativa. In general, the information can be divided into needs or problem areas, obstacles to utilizing existing services, and proposed solutions. In addition, a simple description of the conference attendees is desirable.

Information from Parents. It is likely that no single data source will provide information on each topic identified in this plan. However, each topic should be covered by at least one data collection method. Because any questionnaire needs to be short, the questions it will contain will need to be open-ended and/or highly selective. If appropriate, closed-end questions should be written. They could be used on several different forms of the questionnaire.

Group discussions and discussion booths will probably sample each content area, but there is no way of knowing what specific topics will be covered. However, the recording format should help interviewers categorize the information prior to giving it to us.

Information from Professionals. Information gathered from professionals should relate to the same content blueprint, however, they should have a different questionnaire to avoid branching questions (e.g., if you are a professional, fill this out).

A. Client Characteristics

1. Age of developmentally disabled individual

2. Handicap
   a. type of handicap
   b. severity of handicap (mild, moderate, severe)

3. Vocational status
   a. presently working
   b. work history
   c. support services needed to work
   d. vocational training received
   e. vocational and related training needed
   f. services: testing, counseling, job search skills, OJT, off-job training, D.R., other agency

4. Services currently receiving
   a. social services
   b. medical
   c. educational
   d. vocational

   Examples:

info and referral	self-care training
public school, private school	genetic counseling
recreation	social skills training
residential, short- or long-term	advocacy
respite care, sitters	diagnosis and evaluation
parent education	family counseling
transportation	special equipment
mobility training	admission and discharge planning
sex education	legal assistance

5. Other client characteristics
   a. family size
   b. marital status of client, family
   c. transportation availability
   d. siblings reaction to client
   e. size of dwelling
   f. any dd siblings

B. Obstacles/Problems

1. Needed services

2. ~~Obstacles to~~ receiving services
   a. time lag
   b. cost
   c. language
   d. services not available or inappropriate
   e. paperwork
   f. prejudice
   g. other barriers

C. Parent's Knowledge and Attitudes

1. P&rent attitudes toward
   a. regional center
   b. vocational services/appropriateness of dd working
   c. public school
   d. independent living/mobility training
   e. respite care, out-of-home and institutional care
   f. sex education/marriage

2. Parent knowledge of
   a. client rights
   b. PL 94-142
   c. Sect. 504

Appendix B

This appendix contains copies of the data collection instruments. They are presented in the following order:

1. Parent Questionnaire (Spanish version)
2. Parent Questionnaire (English version)
3. Professional Questionnaire (English version)
4. Reporting forms for the Group Discussions (5 pages)
5. Reporting forms for the Discussion Booths (4 pages)

FIESTA EDUCATIVA '90
Cuestionario para los Padres

La siguiente información se usará para ayudar a mejorar los programas y servicios para las personas de habla hispana con incapacidades del desarrollo. Favor de completar este cuestionario y devolverlo hoy a uno de los dos Puestos Especiales de Discusión. Si usted tiene alguna pregunta acerca de este cuestionario, favor de ir a los Puestos Especiales de Discusión. Muchas gracias por su ayuda al darnos la información importante que beneficiará a los niños de habla hispana con incapacitación de desarrollo y a sus familias.

1. La edad de mi hijo/a incapacitado del desarrollo es _____.

2. Tengo un/a ☐ hijo ☐ hija (indique lo apropiado)

3. Su incapacidad es (marque el cuadro apropiado)
   - ☐ retraso mental
   - ☐ síndrome de Down (anteriormente mongolismo)
   - ☐ incapacitado físicamente
   - ☐ desordenes en el habla y en la lengua
   - ☐ parálisis cerebral
   - ☐ epilepsia
   - ☐ autismo
   - ☐ otra (describa) _____
   - ☐ no estoy seguro/a

4. Su incapacidad es
   - ☐ leve
   - ☐ moderada
   - ☐ severa

5. En los últimos años, ¿cuáles han sido sus mayores problemas al obtener servicios para su hijo/a? (Piense en todo tipo de servicios, médicos, sociales y otros. Indique todo lo que se aplica al caso.)
   - ☐ El personal de la agencia no habla español
   - ☐ Demasiados papeles que llenar
   - ☐ Discriminación a personas de habla hispana
   - ☐ La agencia era demasiado lenta
   - ☐ Falta de cooperación de los profesionales
   - ☐ No había información acerca de los servicios disponibles
   - ☐ Demasiado caro
   - ☐ Los servicios que necesitaba yo no existían
   - ☐ No tenía transportación
   - ☐ Otro (describa) _____

6. ¿Qué nuevo tipo de servicio o ayuda le sería a usted de mayor beneficio en el cuidado de su hijo/a?
   _____
   _____

7. ¿Cuál ha sido su mayor preocupación acerca de su hijo/a este año?
   _____
   _____

8. ¿Cuál es su mayor preocupación para el futuro de su hijo/a (cuando él/ella sea adulto)?
   _____
   _____

9. ¿Ha estado en juntas donde se preparó un Plan de Educación Individualizada (IEP) para su hijo/a? (Indique su respuesta.)
   - ☐ sí, he asistido a una junta del IEP
   - ☐ no, no he asistido a una junta del IEP
   - ☐ no sé lo que es el IEP

10. ¿Está recibiendo su hijo/a educación pre-vocacional (preparación para el entrenamiento para empleo)?
    - ☐ sí
    - ☐ no

11. ¿Está recibiendo su hijo/a educación vocacional (entrenamiento para empleo)?
    - ☐ sí
    - ☐ no

12. Si su hijo/a está recibiendo o ha recibido algún tipo de entrenamiento para empleo, ¿cómo describiría el programa?
    - ☐ buena preparación para trabajar
    - ☐ normal
    - ☐ deficiente—no sirvió para las necesidades de mi hijo/a

    Comentarios _____

13. ¿Está trabajando su hijo/a en algún tipo de taller o empleo especial?
    ☐ sí ☐ no

14. ¿Está trabajando su hijo/a en un empleo normal?
    ☐ sí ☐ no

16. ¿Puede su hijo/a utilizar el transporte público?

☐ sí ☐ no ☐ es demasiado joven

18. De tiempo en tiempo, me gustaría tener una persona capacitada para que cuidara a mi hijo/a por un día o dos.

☐ sí ☐ no ☐ no estoy seguro/a

17. La educación sexual en la escuela es

☐ apropiada para mi hijo/a
☐ inapropiada para mi hijo/a
☐ no estoy seguro/a

18. Cuando mi hijo/a incapacitado/a sea adulto, él/ella

☐ probablemente vivirá en casa
☐ probablemente no vivirá en casa
☐ no estoy seguro/a

19. Cuando mi hijo/a sea adulto, él/ella

☐ probablemente tendrá trabajo
☐ probablemente no podrá tener un trabajo
☐ no estoy seguro/a

20. ¿Con qué Centro Regional para los Incapacitados de Desarrollo está registrado su hijo/a?

_____ _____

21. ¿Qué ayuda le ha dado a usted y a su hijo/a el Centro Regional para los Incapacitados de Desarrollo?

☐ mucha ayuda
☐ alguna ayuda
☐ ninguna ayuda

Comentarios: _____ _____

_____

22. ¿Qué ayuda le ha dado a usted y a su hijo/a el Departamento de Rehabilitación?

☐ mucha ayuda
☐ alguna ayuda
☐ ninguna ayuda
☐ mi hijo/a es demasiado joven

23. ¿Cuánto entrenamiento ha recibido usted en los últimos dos años para padres de niños incapacitados?

☐ mucho (más de 5 programas de educación de padres)
☐ un poco (2 a 4 programas de educación de padres)
☐ muy poco (1 programa de educación de padres)
☐ nunca he tenido ningún entrenamiento o educación de padres aparte de esta Fiesta

24. ¿Es usted miembro de un grupo de padres o de un grupo de defensa de los derechos de las personas que tienen incapacidades?

☐ sí (¿qué grupo?) _____
☐ no
☐ no estoy seguro/a

25. Número de otros hijos en su casa _____

26. ¿Hay otras personas en su familia que necesitan servicios médicos o sociales?

☐ sí ☐ no ☐ no estoy seguro/a

27. ¿Su esposo/a asistió a la Fiesta?

☐ no soy casado/a ☐ sí ☐ no (razón) _____

_____

28. ¿Qué cree usted que le fue más útil de la Fiesta Educativa '80?

_____

_____

29. ¿Qué le gustaría cambiar o mejorar para la próxima Fiesta Educativa?

_____

_____

Muchísimas gracias. Favor de dejar este cuestionario en uno de los Puestos Especiales de Discusión.

Si usted quiere darnos más información sobre las necesidades de los niños incapacitados de habla hispana y de sus familias, favor de anotar su nombre y número de teléfono.

(Opcional) Nombre: _____ Teléfono: (___) _____

N. de área

FIESTA EDUCATIVA '80
Parent Questionnaire

The following information will be used to improve programs for Spanish-speaking, developmentally disabled persons. If you have questions about this survey, please go to a discussion booth. Thank you for helping provide important information that will benefit Spanish-speaking, disabled children and their families.

1. My developmentally disabled child's age is _____.

2. My child is
   - ☐ male
   - ☐ female

3. His/her disability is (mark every appropriate square)
   - ☐ mental retardation
   - ☐ Down's syndrome (mongolism)
   - ☐ physical handicap
   - ☐ cerebral palsy
   - ☐ epilepsy
   - ☐ speech and language disorder
   - ☐ autism
   - ☐ other (describe) _____
   - ☐ don't know

4. His/her disability is considered to be
   - ☐ mild
   - ☐ moderate
   - ☐ severe

5. In the last two years, what have been your biggest problems related to services for your child? (Think about all types of medical, educational, vocational, social, and other services. Check all that apply.)
   - ☐ Agency staff couldn't speak Spanish
   - ☐ Too much paper work
   - ☐ Agency too slow
   - ☐ Agency staff seemed prejudiced against Spanish speaking people
   - ☐ Lack of information about existing services
   - ☐ Services too expensive
   - ☐ Needed services not available
   - ☐ Lack of cooperation from professionals
   - ☐ Lack of transportation
   - ☐ Other (describe) _____

6. What new service or type of help would be most beneficial to you in caring for your child?
   _____
   _____

7. What have you worried most about this year for your child?
   _____
   _____

8. What do you worry most about for your child's future (when he/she is an adult)?
   _____
   _____

9. I have been in meetings where an Individualized Education Plan (IEP) was prepared for my child.
   - ☐ yes, I have attended an IEP meeting
   - ☐ no, I haven't attended an IEP meeting
   - ☐ I don't know what an IEP is

10. Is your child receiving pre-vocational education (preparation for job training)?
    ☐ yes ☐ no

11. Is your child receiving vocational education (job training)?
    ☐ yes ☐ no

12. If your child is receiving or has received some type of job training, how would your describe the program?
    - ☐ good preparation for work
    - ☐ fair
    - ☐ poor—did not meet my child's needs

    Comments _____

13. Is your child presently working at some type of sheltered workshop or special job?
    ☐ yes ☐ no

14. Is your child presently working at a regular job?
    ☐ yes ☐ no

15. Is your child able to use public transportation?
    ☐ yes ☐ no ☐ too young

16. From time to time, I would like to have a qualified person take care of my child for a day or two.
- ☐ yes
- ☐ no
- ☐ not sure

17. Sex education in school is
- ☐ appropriate for my child
- ☐ not appropriate for my child
- ☐ not sure

18. When my disabled child becomes an adult, he/she will
- ☐ probably live at home
- ☐ probably not live at home
- ☐ not sure

19. When my child becomes an adult, he/she will
- ☐ probably have a job
- ☐ probably not be able to have a job
- ☐ not sure

20. Which regional center is your child registered with? _____

_____

21. How helpful has the Regional Center for the Developmentally Disabled been for you and your child?
- ☐ very helpful
- ☐ somewhat helpful
- ☐ not helpful

Comments _____

_____

22. How helpful has the Department of Rehabilitation (vocational rehabilitation) been for you and your child?
- ☐ very helpful
- ☐ somewhat helpful
- ☐ not helpful
- ☐ my child is too young

Comments _____

_____

23. How much training have you had in the past two years that was designed for parents of disabled children?
- ☐ a lot (more than 5 parent education programs)
- ☐ some (2 to 4 parent education programs)
- ☐ very little (1 parent education program)
- ☐ I have never had any parent training or education other than this Fiesta

24. Are you a member of a parent group or advocacy group that helps people who have disabilities?
- ☐ yes (what group? _____)
- ☐ no
- ☐ not sure

25. Number of other children at home. _____

26. Are there other people in your family who need social or medical services?
- ☐ yes ☐ no ☐ not sure

27. Did your husband/wife attend the Fiesta?
- ☐ not married ☐ yes ☐ no (reason) _____

_____

28. What did you find most helpful about Fiesta Educativa '80?

_____

_____

29. What would you like to see improved or changed for next year's Fiesta Educativa?

_____

_____

Thank you very much. Please leave this form at one of the discussion booths.

If you would be willing to give more information about the needs of Spanish-speaking, disabled children and their families, please list your name and telephone number.

(optional) Name: _____ Telephone: (___) _____
Area code

FIESTA EDUCATIVA '80
Professional Questionnaire

The following information will be used to improve programs for Spanish-speaking, developmentally disabled persons. If you have questions about this survey, please go to a discussion booth. Thank you for helping provide important information that will benefit Spanish-speaking, disabled children and their families.

1. How old are most of your clients?

- ☐ 5 years or under
- ☐ 5-12
- ☐ 12-18
- ☐ 18-25
- ☐ 25-45
- ☐ 45-65
- ☐ 65 or over

2. Which of the following is your primary work setting?

- ☐ school
- ☐ hospital
- ☐ vocational rehabilitation
- ☐ regional center
- ☐ other (specify)

_____

_____

3. What do you consider to be the most difficult problem(s) confronted by Spanish-speaking people when they attempt to obtain services (e.g., medical, educational, vocational, social) for their developmentally disabled children? Check all that apply.

- ☐ language barriers
- ☐ transportation problems
- ☐ amount and complexity of paper work
- ☐ high cost of services
- ☐ lack of information about existing services
- ☐ needed services not available
- ☐ slow processing by service agency
- ☐ other (specify) _____

_____

_____

_____

_____

4. What new services or changes in existing services do you feel are most needed by Spanish-speaking, developmentally disabled persons and their families? (Please describe below.)

_____

_____

_____

_____

_____

5. What did you find most helpful about Fiesta Educativa '80?

_____

_____

_____

6. What would you like to see improved or changed for next year's Fiesta Educativa?

_____

_____

_____

Thank you very much. Please leave this form at one of the discussion booths.

If you would be willing to give more information about the needs of Spanish-speaking, disabled children and their families, please list your name and telephone number.

(optional) Name: _____ Telephone: (___) _____
Area code

Discussion Group Leader _____

Discussion Group Recorder _____

QUESTION 1

What specific kinds of problems have you experienced that prevented you from receiving available services?

Discussion Group Leader _____

Discussion Group Recorder _____

Discussion Group Leader _____

Discussion Group Recorder _____

QUESTION 3

What kinds of non-vocational training should developmentally disabled persons receive in order to make them more independent?

Discussion Group Leader _____

Discussion Group Recorder _____

QUESTION 4

What kinds of education, training, and other services should be provided to help Spanish-speaking, developmentally disabled persons become successful workers?

Discussion Group Leader _____

Discussion Group Recorder _____

QUESTION 5

What special characteristics of the Spanish-speaking community/family need to be understood by people who provide services for the developmentally disabled?

Interviewer _____ Page _____

Item Number	Question or Comment

Interviewer _____

QUESTION 1

What is the biggest problem you personally have in caring for your developmentally disabled child?

Medical Care

Behavior

Family Stress

QUESTION 1 Continued

Interviewer _____

Attitudes toward disabilities

Attitudes toward professionals

Other

Interviewer _____

QUESTION 2

What are the educational and job training needs of your child?

Interviewer _____

QUESTION 3

Would parent training programs be helpful to you? If so, what specific kinds of training do you need most?

No

Yes (describe)

Appendix C

This appendix contains the guidelines that were prepared for the data collection personnel. The guidelines for the group discussion leaders and recorders are presented first, followed by guidelines for the discussion booth interviewers.

GUIDELINES FOR
DISCUSSION GROUP LEADERS AND RECORDERS

Thank you for agreeing to act as a group leader or recorder for Fiesta Educativa '80. Today you have been given an overview of the types of information collection activities that will be conducted related to the Fiesta.

Now, through discussion and practice, you will learn exactly what your particular responsibilities will be. These guidelines suggest a step-by-step approach for carrying out each task. We hope that you will find them useful.

Preparing for the Discussion Session

1. Before the Fiesta begins, locate the room in which your discussion group is to meet. Check to see that the seating is adequate, and that the chairs are arranged to stimulate conversation (a circle will probably be preferred in most groups). No special equipment or materials are required. However, recorders, don't forget to bring your set of forms and a clipboard to the session.

Conducting the Discussion

2. Leaders, once the group members have arrived but before the discussion begins:

   - Welcome the participants.
   - Introduce yourself and the recorder, and ask the group members to give their names.
   - Clarify that the purpose of the small group discussions is to hear how the group members feel about several issues related to problems in the services provided for Spanish-speaking developmentally disabled persons. Group members will also be asked to share their ideas about how these services could be improved and what new services are needed.
   - Emphasize that this discussion is important because the information that is collected will be reported to state agencies that determine the services available for the disabled.

- Explain that your role is to keep the group "on the subject" and to see that everyone has a chance to talk (sometimes by limiting comments on each topic to several minutes per person).

- Explain that the recorder's role is to take down the thoughts and suggestions of the group members, and then to prepare this information for use by the Regional Centers and state agencies of developmental services and rehabilitative services. Make sure that the participants understand that, in order to be accurate and thorough, the recorder may from time to time during the discussion request that a point be repeated or clarified.

3. Five topics should be covered during the 90-minute discussion period. This will allow about 15 minutes to be devoted to each topic, with some time for summarizing by you and additional remarks from the group members.

   To begin the discussion, read all five of the questions so that the participants will know what issues are to be dealt with. Then proceed item-by-item through the list, following the procedures shown below.

   - State the question and determine that the group members understand what is being asked.

   - Call for responses from the group members.

   - Keep the discussion focused and calm.

   - See that everyone is asked to contribute, even nonvolunteers.

   - Ensure that the recorder has understood each response and has had time to take it down.

   - Summarize the responses at the conclusion of each topic and ask for any additional comments.

QUESTIONS TO BE ASKED DURING THE DISCUSSION PERIOD	SOME POSSIBLE AREAS OF RESPONSE
1. What specific kinds of problems have you experienced that prevented you from receiving available services?	Language Paperwork Lack of information about the service Service too slow Lack of cooperation from professionals Cost Transportation Prejudice
2. How would you change the services that are now available, or what new services or programs would you add, in order to better meet your child's needs and your own?	More bilingual staff Cultural awareness training for staff Simplified forms Transportation provisions Training for parents
3. What kinds of non-vocational training should developmentally disabled persons receive in order to make them more independent?	Self-care skills Mobility training Independent-living skills Sex education
4. What kinds of education, training, and other services should be provided to help Spanish-speaking developmentally disabled persons become successful workers?	Assessment and counseling Physical adaptation of work facilities Social skills training Job skills training On-job training and supervision Job search programs Public school programs Career education
5. What special characteristics of the Spanish-speaking community/family need to be understood by people who provide services for the developmentally disabled?	Language Family customs Religion Attitudes toward disabilities Attitudes toward professionals

4. Shortly before the discussion session is to adjourn:

   - Thank the parents for their participation in the discussion.

   - Let them know that their comments will be incorporated into a report prepared by SWRL and submitted to the California State Department of Developmental Services and the State Department of Rehabilitation. This report will provide a basis for making changes in and additions to programs for Spanish-speaking developmentally disabled persons. A summary of the report will be available from ELARC and from the Los Angeles County Inter-Regional Center Committee for the Spanish Speaking.

After the Discussion

5. Leaders, immediately after the group members have gone, meet with your recorder to review the notes that have been taken. If any points seem to require clarification, elaborate as necessary but do not rewrite parent comments. These should be stated in the original words of the participants.

   Also during this time, decide what major points were made in the discussion and reach an agreement regarding the overall tone of the session. A summarizing paragraph containing this information should then be appended to the recorder's notes.

6. Recorders, following the Fiesta, organize the material into categories (rewriting or typing it for purposes of legibility, if necessary) and to add additional explanatory remarks if this seems appropriate. Be sure to include the summarizing paragraph referred to in item 5 above.

   If possible, confer with the group leader once more to review and jointly approve the final version of the discussion notes; then mail them to Bill Brock at SWRL, 4665 Lampson Avenue, Los Alamitos, California 90720. Please save a copy of the notes that you send to SWRL, in case they are lost in the mail. All notes should be mailed to SWRL within four days of the Fiesta.

GUIDELINES FOR DISCUSSION BOOTH INTERVIEWERS

Thank you for agreeing to be a discussion booth interviewer for Fiesta Educativa '80. Today you have been given an overview of the types of information collection activities that will be conducted related to the Fiesta.

Now, through discussion and practice, you will learn exactly what your particular responsibilities will be. Although some professionals attending the Fiesta may ask questions or offer comments regarding the questionnaire, you will for the most part be helping parents with their responses and talking with them about their problems, their needs, and their child's needs. These guidelines are geared to that aspect of your duties and suggest a step-by-step approach for carrying out each task. We hope that you will find them useful.

Preparing the Booth

1. Before the Fiesta begins, check your booth to make sure that chairs and tables (or other writing surfaces) have been provided and that necessary writing materials are available. Don't forget to bring your interview forms with you.

Operating the Booth

2. As parents approach the booth:

   - Greet them and ask them to be seated.
   - Introduce yourself and put the parents at ease.
   - Make sure that the parents understand how the information on the questionnaire will be used. (See item 7 of these guidelines.)

3. First respond to any questions the parents may have regarding the questionnaire in its entirety or particular items on the questionnaire. All parent inquiries should be dealt with before any new issues are introduced.

Each time you help parents with an item on the questionnaire, enter on your interviewer's form the item number and the parents' questions or comments. Explain to the parents that you are doing this so that all questions that are confusing or unclear can either be reworded or, in some cases, omitted from future information gathering materials. Remember always to write the questions or comments in the form given by the parents. Ask them to clarify if necessary, but don't restate, or otherwise "interpret" their remarks.

4. After the parents' questions have been answered and their responses have been entered on the form, quickly check the remaining items on the questionnaire to ensure that they have all been completed, or ask the parents to do it. Give special attention to items 5 and 6, which relate to service problems and service needs, as this information is very important to the agencies sponsoring the Fiesta.

5. Next, ask the parents what is the biggest problem they personally have in caring for their developmentally disabled child, e.g., medical care, nutrition, behavior, attitudes of brothers and sisters, family stress, costs, transportation, etc. (This is Question 1 in your interview forms.) Record their comments, along with any suggestions they make regarding what might be done to help them with this problem.

6. If time permits and the parents seem willing to continue the discussion, ask the remaining two questions (shown below) and record the parents' responses.

   Question 2: What are the educational and job-training needs of your child?

   Question 3: Would parent training programs be helpful to you? If so, what specific kinds of training do you need most?

7. In concluding the discussion:

   - Thank the parents for their help.

   - Explain that SWRL will use the information gathered at the Fiesta to compile reports for the California State Department of Developmental Services and the State Department of Rehabilitation. These reports will provide a basis for making changes in and additions to programs for Spanish-speaking developmentally disabled persons.

After the Fiesta

8. Use these copies to organize the material into major topic areas (rewriting or typing it for purposes of legibility, if necessary); then mail the revised versions to SWRL within four days of the Fiesta. Mail the forms to Bill Brock, SWRL, 4665 Lampson Avenue, Los Alamitos, California 90720. Be sure to save a copy of the forms you mail to Bill Brock, in case they are lost in the mail.

Appendix D

This appendix contains the coding system that was used to categorize responses to open-ended questionnaire items (i.e., questions 6, 7, and 8 on the parent questionnaire, and question 4 on the professional questionnaire). The coding system was developed using a subsample of the total number of questionnaires received.

Coding System for:
Parent Questionnaire Items 6, 7, and 8
Professional Questionnaire Item 4

Each open-ended response was coded by determining which category most adequately described the response (either as a need or a problem).

Code #	Category Description
01	physical abilities, ambulation, mobility, and self care skills
02	speech and expressive language skills
03	more services of all types
04	bilingual services and staff
05	medical services
06	transportation services
07	parent training and education
08	educational services keyed to handicapped
09	financial assistance
10	more equipment and assistive devices
11	improved information and referral services for parents
12	child care services and/or respite care services
13	better assessment of child's disability
14	residential care services, placement services
15	better quality service staff in general
16	services for families of undocumented workers
17	recreational services
18	ability to care for self adequate for independence, self-protection skills
19	continuing training after age 21
20	care after the parents die
21	social skills and sex education training for adolescents
22	information about the permanence of the disability
23	changes in behavior as child grows older and methods for behavior control
24	employment and independent vocational skills
25	general concern and pessimism about the future
26	family counseling services
99	could not be coded or missing